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ABSTRACT

The paper looks at epilepsy, with emphasis on student problems and the role of the teacher. Initial sections describe characteristics of absence seizures, generalized tonic-clonic (grand mal) seizures, and complex partial seizures. The educator's role is considered relating to three areas: medical problems, social problems, and psychological problems. Among the suggestions offered to the teacher are to know enough about the disorder to feel comfortable with a child having the disorder, to prepare classmates with information, to help the student deal with his own feelings, and to seek guidance when necessary. Appended are a table of first aid procedures for dealing with seizures and a list of suggested student materials on epilepsy. (SW)

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TEACHING THE STUDENT WITH EPILEPSY:

A DILEMMA OR AN OPPORTUNITY

Prepared for Presentation at

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of

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Teaching the Student With Epilepsy:
A Dilemma or an Opportunity

All people are handicapped in some way at sometime in their life. It may be a short-term handicap such as a broken arm, a fairly common handicap such as being near-sighted, or a chronic handicap such as diabetes.

Public Law 94-142 has forced schools to look at and deal with children who have serious handicaps. Schools are now providing services for blind students, deaf students, students with cerebral palsy and other major disorders. The greatest need of these students is a need for self esteem which results from knowing they are respected as human beings. This factor will affect not only their scholastic achievement, but their ability to cope successfully with life. Let us look at the disorder called epilepsy. What dilemma does it present for the student and the teacher? What opportunity does the teacher have to affect the life of the student with epilepsy?

Having a Seizure

Have you ever seen a seizure?

Have you ever had one?

Would you like to have one?

I have asked thousands of persons that question, and have yet to find someone that wants to have one. Yet it is possible for you to have one, since everyone has a seizure threshold. That threshold varies for each individual, and if you have never had a seizure, you probably have a normal threshold. It would be possible to submit your body to enough physiological factors to influence your threshold to the point where a seizure could be elicited. Let's assume that you would be willing to submit yourself to whatever is necessary to have a seizure. How would we lower your threshold? Do you like to sleep? We will start by depriving you of any sleep. Do you like to eat? We will also deprive you of food. How do you manage stress? What if your spouse surprised you with divorce proceedings, your teenager was arrested on a drug charge, and your principal told you they would not be able to rehire you next year?

You have now been without sleep or food for a week, and have many stress factors in your life. All of these factors would be lowering that seizure threshold, and were we to continue this course it is conceivable that you would have a seizure.

The person with epilepsy has a threshold which is lower than normal. The same factors which could cause you to have a seizure can cause persons with epilepsy to have one--but the lower threshold results in them having a tendency for recurrent seizures. We define

epilepsy as a disorder of the central nervous system with a tendency for recurrent seizures. We can actually measure the disturbance within the central nervous system by means of the electroencephalogram. In this test, wires are attached to the head and the electrical impulses of the brain are recorded on paper. Abnormal electrical discharges of the brain are outwardly exhibited by the behavior of the body. We, therefore, define a seizure as a paroxysmal uncontrolled episode of abnormal behavior associated with abnormal electrical discharges within the brain.

What are these abnormal behaviors? There are over 20 different seizure types which exhibit themselves in different ways. Three of these types are more common and we will concentrate on the characteristics of these three.

Absence Seizures

Absence seizures usually occur during childhood. It is a very subtle seizure which lasts for a matter of a few seconds. The EEG indicates a short burst of abnormal electrical discharge within the brain. The only outward sign of the seizure is staring, eyes rolling upward, or eyes blinking. The child is able to resume normal activity immediately. For the child it has been a brief period of blackout. The problem is that during this blackout the child has missed your instructions. To make matters worse, if the child's seizures have not been detected, there may be two or three hundred of these small blackouts in a day. What is your normal reaction as a teacher each time that child has missed instructions and does not know what problem to do or how to respond appropriately to your question? If this happens 100 times a day what do you do? As you become frustrated and constantly nag at the child to pay attention, what happens to that child's self-esteem? In total frustration the student with this problem may either become withdrawn or become a behavior problem. The solution to the problem lies in:

1) Early detection and diagnosis (teachers can be excellent case finders of this type of seizure).

2) Medication which can control the seizures.

3) Patience on the part of the teacher and fellow students who must be willing to respond positively when asked to repeat what they just said. This positive response is a major factor in protecting the child's self-esteem.

Generalized Tonic-Clonic Seizures

Generalized tonic-clonic (grand mal) seizures are the type with which most people are familiar. With this seizure the student may seem perfectly normal one minute and be convulsing the next moment. The first indication of a seizure may be the "cry" heard as the air

is forced out of the diaphragm past the vocal cords. The person will fall to the ground and become rigid (the tonic phase). This is followed by the clonic phase during which the muscles begin rapid alternate periods of spasm and relaxation. Breathing is labored or may cease completely, causing the person to turn blue. The person may also lose control of the bladder and the bowels.

The abnormal activity you witness is a direct result of the abnormal electrical discharge within the brain, as seen on the EEG recording.

Imagine the scene in your classroom if a student suddenly has this type of seizure. It is at a moment when you have captured the attention of your students with some fascinating explanation of the subject matter at hand. As the cry that signals the beginning of the seizure is heard, what happens to you? How do you feel as you witness the seizure behavior? What about the classmates? How do they react to the situation? The reaction of observers is often one of fear, repulsion, and panic. In the brief space of two-minutes, complete pandemonium can ensue. The student who had the seizure comes to and must cope with:

1) the physical exhaustion and aches of a seizure;

2) the undesirable position of being the center of attention;

3) possibly the embarrassment of soiled clothes;

4) a lack of understanding of what has happened;

5) the anger and frustration of having this disorder over which there is no personal control.

The end result is a decrease in self-esteem.

Complex Partial Seizures

The final seizure type which we want to consider is a complex partial seizure. If you look at the EEG of a person having a partial seizure, you will see that it differs from absence and generalized tonic-clonic seizures in that the latter types show abnormal electrical discharges throughout the entire brain, but in a partial seizure, the abnormality is only in certain areas. Because this abnormality may be in different areas of the brain, you may have two people with complex partial seizures who exhibit different behaviors during the seizure. The important common factors of all complex partial seizures are a decreased awareness of the environment and a purposeless activity. These purposeless activities may include lip smacking, mumbling, wandering, picking at clothes, and automatic repetition of some movement.

Once again, I ask you to picture your classroom filled with attentive students. What is your reaction if a student suddenly stands

and starts wandering around making unintelligible sounds? How do you feel when you call the student by name and ask that he or she be seated only to have the student look at you with a puzzled or blank expression and then continue the wandering? What is the reaction of the other students? Frequently, observers of this seizure conclude that the individual is drunk, on drugs, or psychotic. As the person gradually comes out of the seizure, there is usually confusion as to where he or she is and what is going on. The individual also frequently encounters an upset teacher and laughing classmates, and is puzzled by everyone's reactions. What does that do for the student's self-esteem?

I asked you earlier if any of you would care to have a seizure. People do not want seizures because they do not want to lose control of themselves. They do not want to suffer the embarrassment which accompanies the seizures just described. If you feel that having just one seizure would cause you distress, can you understand the distress with which the student who has epilepsy must live? Even if the seizures are well controlled with medication, the person frequently continues to live with the embarrassment of that first seizure and the fear of it happening again. The individual with epilepsy suffers from the continual uncertainties of the disorder. This is true of any chronic condition, but there is an added dimension to those who have a "hidden handicap" such as epilepsy. Persons who are blind or in a wheelchair must learn to adjust to the blindness or the wheelchair. They grow accustomed to it because it is constantly present--both for themselves and for others. The person with a hidden handicap does not come to this adjustment as readily, due to the fact that he or she seems perfectly normal most of the time. The episodic nature of the disorder lends an uncertainty which makes adjustment difficult. Just when you feel you have it licked, a problem arises.

The Role of the Educator

What can the educator do to resolve some of the problems that destroy the self-esteem of the student with a chronic hidden disorder? I would suggest the need for providing assistance in three areas:

1) The medical problems.

2) The social problems.

3) The psychological problems.

In the area of the medical problems, the first step is for you to know enough about the disorder to feel comfortable with a child in your classroom having that disorder. A disorder is usually not as bad as we think it is. If we learn a little bit about it we can look at a student and say, "There is John." Without the appropriate knowledge we may look at the student and unconsciously say, "There is Epilepsy," which is tantamount to saying, "There is Leprosy."

Included in the knowledge about the disorder is the necessity to be aware of the appropriate first aid needed in case of emergency. This aid is often surprisingly simple, with the most crucial factor being, "Don't panic." (See appendix for appropriate first aid.)

It is also important to have some knowledge about the medications the child is taking. These medications may have side effects and you need to know what those side effects are. Frequently you can be the one who notices a change in the student which indicates a need for monitoring by the physician.

Finally, you need to know what limitations the person has because of the disorder. It is important for the development of a healthy self-esteem and normal growth of independence that there be as few physical limitations as possible placed on the student. A physician's statement regarding limitations on the child's activities is appropriate.

On the other hand, you need to be aware of limitations which may affect the child's education. For example, for the child with epilepsy, learning may be hampered by time lost during seizures, medication problems, or neurological difficulties associated with the epilepsy. Teachers need to be aware of these potential problems, and make adjustments to help the student who is encountering difficulties.

Social Problems

If you have prepared yourself for the medical problems, you also have prepared yourself to help overcome the social problems the student faces. Classmates need the same information you needed to feel comfortable with the student who has a hidden handicap. They need to understand the physiological explanation of what is happening when a student has a seizure. If they understand, they can be comfortable with that person and will not avoid contact with him or her. It is extremely important that teachers take time to answer questions and talk about feelings of classmates following a seizure or a physical problem with any handicapping condition. The ideal is preparation of students before an emergency arises. Many schools are addressing this need through handicap awareness programs. An excellent curriculum for such a program has been developed by Susan R. Bookbinder and is entitled Mainstreaming: What Every Child Needs to Know About Disabilities, (Published by the Exceptional Parent Press, Room 708, Statler Office Building, Boston, MA 02116). This curriculum consists of units on blindness, deafness, physical disabilities, and mental retardation.

Curriculum materials on epilepsy are also available for all ages. These materials include:

Because You Are My Friend: (grades K-1)
Epilepsy Is... Program I (grades 2-3)
Me and My World (grades 4-6)
Epilepsy Is... Program II (grades 7-12)

All of these materials are available from the Epilepsy Foundation of America. (See appendix)

Programs such as these are proving very effective in helping students develop positive attitudes towards the handicapped. Following a class on blindness one student reported to his teacher, "I helped a blind person across the street today. I would have been scared to do that before our lesson on blindness." After the lesson on epilepsy a fifth grade class who had been ostracizing and ridiculing a classmate with epilepsy completely changed in actions towards the child. It is a matter not of focusing on one facet of that individual, but of being open to accept the limitations and appreciate the abilities of that unique person. It is the concept of each individual having dignity and value.

Psychological Problems

What is the educator's role in regard to the psychological needs of the student with a disability? This is the most difficult phase, but the teacher who has worked through the medical problems and the social problems has already done a great deal towards helping that student with self-esteem. If you are comfortable with the child, that child is more likely to be comfortable with you. If you have helped to educate the entire class in regard to the handicap, you have also helped to teach the student important facts about the disability. Frequently no one has thought to explain the disorder to the child. The student often has questions about the disorder which he or she has never asked. Added to personal questions, the child is often painfully aware that the disorder is causing the family a great deal of anxiety.

The school with an understanding teacher and understanding classmates is an important support for the student. Once the facts are known about the disorder, the most important thing to do is to live out the day as normally as possible. This includes a respect for the individual that demands the student grow towards independence. It calls for the same rights and responsibilities that all students have.

The student with epilepsy may continue to have problems due to the feelings connected with having a disorder. If the individual exhibits unusual withdrawal or aggressiveness, it may be a warning signal of feelings with which he or she is not coping appropriately. The teacher can assist the student and the parents to recognize the need for special guidance.

In summary, there is within your classroom an individual with a handicap. Three components of that classroom are looking at the individual: you, the teacher, the classmates, and the individual looking at him or herself. The teacher can provide a tremendous service by leading the way to seeing that student as a unique individual. The teacher may look and say, "Ah, that's Mary, the girl with a sense of humor, who is good at reading but has trouble with math."

The classmate may look and say, "Oh, there's Mary. She's so cute, and can she ever play a good game of basketball. She's a good one to

ask about the assignment in reading, but I'd be better off asking Sue for help with my math."

And finally, there is Mary, who can look at herself and say, "I'm Mary. I'm best at reading and recess. I do a pretty good job at basketball and I'm fair at volleyball. Don't ask me how to do that math problem. And incidentally, I have epilepsy, but it's no big deal."

All people are handicapped in some way at sometime in their life. It may be a short-term handicap such as a broken arm, a fairly common handicap like being near-sighted, or a chronic handicap such as epilepsy. It is our philosophy that each individual has dignity and value. In accordance with our philosophy we reach out to understand and accept all individuals with various handicaps, and as educators we strive to help others reach out and accept these individuals too.

APPENDIX A

FIRST AID FOR SEIZURES

TYPE OF SEIZURE	CHARACTERISTICS	PHYSICAL AID	PSYCHOLOGICAL AID	SOCIAL AID	SCHOLASTIC AID
Absence	- 1 to 10 seconds long - Stares - Eyelids flutter - Resume activity immediately	- None	- Listening patiently - Repeating what was said when necessary	- Help others understand what is happening - Help develop patient attitude	- "Buddy System" (someone to help keep up with directions, etc.)
Generalized Tonic-Clonic	- 1 to 3 minutes long - May cry out - Fall to ground - Stiffen - Jerking of whole body in rhythmic manner - lose urine or stool - saliva - skin may turn blue - tired after seizure with possible headache/muscle soreness	- Help to lying position - Loosen tight clothing - Place hand under head - Clear area of hard objects - Do <u>not</u> force anything into mouth or restrain person - Turn head to side when seizure subsides	- Reassurance, "It's OK" - Let person know what happened - Chat with person or read to them - Allow to rest if desired - Bring back into group as soon as possible	- Help others understand what's happening - Carry on business as usual - Give others opportunity to discuss it - Help others learn to react in an "accepting manner"	- Aid with work when needed
Complex-Partial	- 2 to 4 minutes long - May smack lips Mumble Wander Pick at clothes Repeat a behavior automatically - Behavior has no purpose - Confused after seizure	- Do <u>not</u> try to restrain - Remove harmful objects - Guide gently away from danger	- Talk gently - Reassure, "It's OK" - Help reorient after seizure - Let them know what happened - Chat with them	- Help others understand - Carry on business as usual - Help others learn to react in an "accepting manner"	- Aid with work when needed

Appendix B

Suggested Materials on Epilepsy for Student Use

Audiovisual

Because You Are My Friend

An automatic slide tape presentation for young children about the basic nature of epilepsy. Narrated by a 7 year old child. (Length: 5 minutes) Purchase Price: $25.00

Epilepsy Is... Program I

An educational audiovisual material which demonstrates what happens when a person has a seizure, describes why it happens, and tells how to give the appropriate aid and support. Designed for children, ages 5-12. (Length: 10 minutes) Purchase Price: Filmstrip/Audio Tape - $20.00; 35mm Slides/Audio Tape - $35.00

Epilepsy Is... Program II

Same as Program I, above, except designed for ages 12-adult. (Length: 15 minutes) Purchase Price: Filmstrip/Audio Tape - $20.00; 35mm Slides/Audio Tape - $40.00

Me And My World

A 15 minute slide tape presentation for children about epilepsy. The presentation gives facts about the condition and, through the device of having children question the narrator during the presentation, provides an opportunity to surface some of the psycho-social issues involved. Primarily designed for children with epilepsy (aged 6-12), siblings, and children with an adult relative with epilepsy, it is also suitable for presentation to classmates of children with epilepsy. (Length: 15 minutes) Purchase Price: $75.00

Books

A Handful of Stars, Barbara Girion, New York, Charles Scribner's Sons, 1981. A sensitive fictional account of a high school sophomore suddenly stricken with epileptic seizures and her struggle to learn to live with her condition as her doctors attempt to control it through medication.

Epilepsy, Alvin and Virginia B. Silverstein, Philadelphia, PA. J.P. Lippincott, 1975. $5.50 (cloth), $1.95 (paperback). Written for children 10 years or older. This book contains a good deal of interesting and accurate information. Highly recommended for adults as well as children.

"All About Epilepsy" available from the Epilepsy Foundation of America, 4351 Garden City Drive, Landover 20785. A booklet written for children ages 8-11. ($.80)

Suggested for Teacher Use

Epilepsy: First Aid for Seizures

A 16mm film which demonstrates the characteristics and appropriate first aid for absence, generalized tonic-clonic and complex partial seizures. Filmed in a restaurant, school and factory, it addresses questions of when transportation to a hospital is necessary, the special needs of children in schools, and appropriate precautions on the job. (Length: 16 minutes) Price: $175.00; also available for rental: $6.00. Contact Materials Service Center, Epilepsy Foundation of America, 4351 Garden City Drive, Landover, Maryland 20785.

All Audio-Visual materials presented in this Appendix are available from:

Materials Service Center
Epilepsy Foundation of America
4351 Garden City Drive
Landover, Maryland 20785